

THE DEAF & HARD OF HEARING & HIV/AIDS



The American Social Health Association estimates that 28 million individuals in the United States are hearing impaired—approximately 10 percent of the population. The deaf and hard of hearing exist within a unique and vibrant culture, a fact not fully appreciated by hearing individuals. Many advocates believe that recognition by the hearing public that a deaf culture exists is a crucial first step toward educating the Nation about the needs of the deaf and hard of hearing who are living with HIV disease.

SURVEILLANCE

Between 8,000 and 40,000 deaf and hard of hearing individuals are living with HIV disease in the United States.¹ This wide range is based on two limited studies, one indicating a seroprevalence rate of slightly less than 1 percent, and the other of about 5 percent. A Maryland study based on test results at federally funded counseling and testing centers, which historically account for no more than 12 to 15 percent of all HIV-positive test results, yielded a 4.3 percent rate.²

National AIDS surveillance data do not include information on hearing status; thus, little is known about the transmission of HIV among the deaf and hard of hearing. However, in 1992, 12 years after the onset of the epidemic in the United States, experts estimated that the deaf population was about 8 years behind the hearing population in its knowledge and awareness about HIV/AIDS.³

CRITICAL ISSUES

Seventy-five percent of the deaf and hard of hearing in the United States use American Sign Language (ASL) as their primary means of communication. English is a common second language, which a deaf or hard of hearing person reads at a 4th grade level, on average. ASL is by far the most effective means of communication with the deaf.⁴

One in 7 deaf people has a history of substance abuse, compared with 1 in 10 in the hearing population.⁵

Of approximately 200 deaf and hard of hearing individuals interviewed by the Minnesota Chemical Dependency Program for Deaf and Hard of Hearing, only 15 percent of respondents from the community demonstrated knowledge of HIV transmission facts.¹

Deaf high school students have much less knowledge about HIV transmission than do their hearing counterparts. The gap is narrower among college students, but it still exists.³

The deaf and hard of hearing are protected under the Americans with

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Disabilities Act. The purpose of this legislation is to provide accommodations to needs that are deemed “universal,” including equal access to health care, education, and employment. However, the Act is not always enforced.

Most individuals erroneously assume that ASL and English are closely related and that most ASL users have high English proficiency. As a result, materials are often culturally inappropriate and linguistically incomprehensible, depriving the deaf and hard of hearing of essential information about HIV/AIDS. Ultimately, the lack of appropriate materials reveals a lack of culturally competent programs and creates enormous barriers to care.

THE DEAF AND HARD OF HEARING & THE RYAN WHITE CARE ACT

Many organizations funded through the Ryan White CARE Act serve people who are deaf and hard of hearing. Additionally, the HIV/AIDS Bureau, which implements the CARE Act, has participated in several projects to promote improved services for this population.

The deaf and hard of hearing receive services through all CARE Act programs. Access to services is facilitated by translators, who can be reimbursed using CARE Act funds.

HIV and the Deaf Population in the United States identifies and discusses major issues regarding the diagnosis and care of HIV-positive deaf and hard of hearing individuals. Copies may be obtained by contacting the bureau's Office of Science and Epidemiology at 301-443-6560.

The HIV/AIDS Bureau took a leading role in the National Meeting on HIV/AIDS and the Deaf and Hard of Hearing Community, which took place in November 2000. A follow-up report outlines next steps for raising awareness of the epidemic among the deaf and hard of hearing and improving access to care. Copies may be obtained through the U.S. Department of Health and Human Services, Office on AIDS Policy, 202-690-5560.

In March 2001, the Bureau published an issue of its newsletter HRSA Care ACTION on HIV/AIDS among the deaf and hard of hearing. The publication is currently available at <http://hab.hrsa.gov>.

The Bureau is working with institutions in the deaf community to update a list of HIV resources for deaf people living with HIV and is exploring ways to disseminate this information to the deaf community.

REFERENCES

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3. Gaskins S. Special population: HIV/AIDS among the deaf and hard of hearing. J Assoc Nurses AIDS Care. 1999; 10(2):75-8.
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